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ABSTRACT

This booklet contains guidelines to help families coordinate health care of a child with asthma. The first section provides general information covering what asthma is, the signs and symptoms of asthma, effects of asthma, and the use and effects of various medications. A section on health care focuses on the use of the Family Centered Health Care Team, periodic health care, and record-keeping. The next section reviews the asthmatic child's needs for health care, proper development, schooling, and day care for each of the following age groupings: infants ages 0-2, preschool children ages 3-5, school-age children ages 6-12, adolescents ages 13-17, and young adults ages 18-21. The next section briefly describes family support services in the areas of advocacy, human services, schools, family support groups and networks, recreation, travel, safety, and siblings. A glossary of about 50 asthma-related terms is provided. A listing of resources includes 8 asthma-specific organizations; 16 books, pamphlets, and videos for children and families; 15 articles and books for health professionals; 7 resources (in Minnesota) for specialty medical care for children with asthma; 21 general organizations for children with special health care needs; 20 general books, pamphlets, videos, and catalogs; and 8 sources of health care financing. (DB)

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Guidelines of Care for Children with Special Health Care Needs

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ASTHMA

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BOOKLET MAY BE REPRODUCED

Information contained in this booklet is meant to supplement the advice of a physician or other health professional. Ask your physician about your child's specific needs.

Credits

Thank you to the many families, physicians and health professionals who shared their expertise and insight for development of the guidelines. Also, thanks to the members of the Ad Hoc Advisory Task Force for their assistance in planning and developing the guidelines.

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INTRODUCTION

These guidelines are written for families and health professionals. They also can be used by anyone who cares for a child with asthma including teachers, school personnel, friends, and relatives. Readers may find different sections of the booklet useful at various times during the child's development.

The primary purpose of the guidelines is to help families coordinate health care that may be needed by a child with asthma. This information may help families determine which services are needed for the optimal growth and development of their child. To do this, families need to understand the health care system and how to use it effectively.

Health care services are a resource for families. They provide information and care for children with special health care needs. Families who are actively involved in coordinating their child's care assure their child better health care. This is because informed, involved families can promote communication with and between health professionals. Informed families also understand how the health care plan meets the needs of their child better than anyone else. Parents know when the plan is not working well for their child. They can identify unmet needs or duplication of services. Parents are encouraged to actively participate with health care providers to assure that the child's needs are met.

The challenge to health professionals is to serve families appropriately and effectively by providing **family-centered care.*** This can be accomplished by providing health care within the context of each family's values, ideals, culture and lifestyle. The family also benefits from **community-based** services, as close to the child's home as possible.

Individual children's needs vary. These guidelines list the most common health care needs of a child with asthma. ***Ask your doctor how your child's health care needs are different from those listed here.***

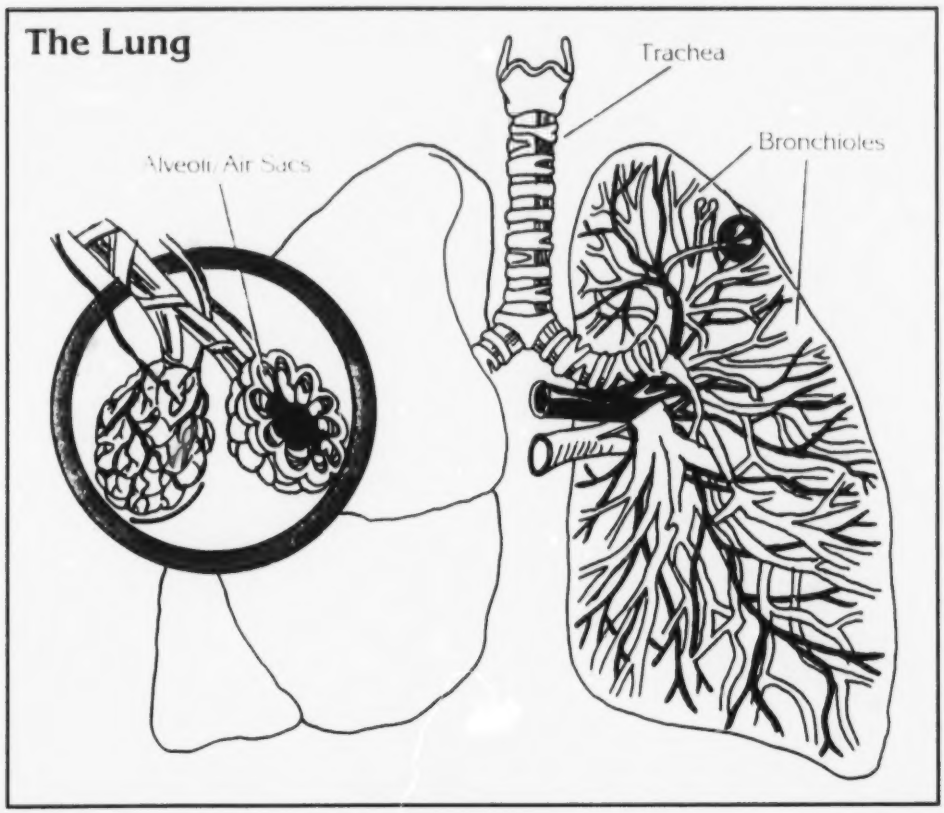
*Words that you see printed in dark type are explained in the Glossary that appears later in this booklet. Turn to the glossary whenever you are not sure of the meaning of a word in dark type.

GENERAL INFORMATION

What is asthma?

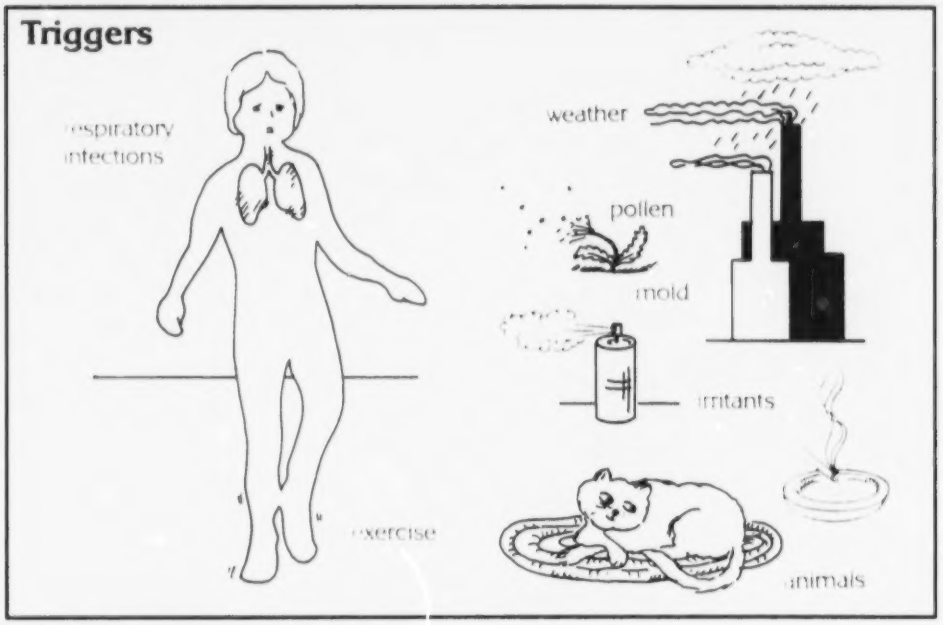
Asthma is a common lung condition that affects about 5-10 percent of American children. Asthma is a major cause of absence from school. By one estimate, asthma accounted for 60 percent of school absences. During elementary school years, more boys than girls have asthma. Uncontrolled asthma can be a serious or life-threatening condition. However, for most children today, asthma can be well controlled.

A person with asthma has **airways** that tighten up when exposed to **triggers** (factors that cause asthma symptoms). This situation is sometimes called "twitchy" airways. In addition, the lining of the airways may swell and become inflamed. The person develops shortness of breath because of narrowed air passages. This difficult breathing is called an **asthma episode**, **asthma flare**, or **asthma attack**. Asthma is also called **reactive airway disease**, because the airways react to triggers by narrowing and cause wheezing and coughing.



What causes asthma?

Asthma is caused by lungs that over-react to **triggers.** Many different types of triggers can cause an **asthma episode**. The triggers are different for every person with asthma. A big part of controlling asthma episodes is knowing which triggers affect your child and avoiding them. ***Control of the environment is the most important way to treat and control asthma!***



Asthma triggers

- Exercise, which cools and dries out the airways
- Respiratory infections from viruses and colds
- Allergies such as those to pollen, dust mites, mold, animals, feathers, and less often, food
- Irritants - smoke from tobacco and wood stoves, aerosol sprays from household products, fumes, paint, powders, bleach, perfume, and many others
- Weather - changes in the weather and breathing cold air or very humid air (temperature, pressure and humidity changes)

Many books on asthma have information on how to allergy-proof a home. The resource section of this booklet lists some of these.

What are the signs and symptoms of asthma?

A person with asthma usually does not have any symptoms between episodes. During an **asthma episode**, the symptoms may include any of the following:

- Coughing
- Wheezing - A whistling sound the person makes when breathing
- Shortness of breath, fast breathing
- Increased **mucus** production

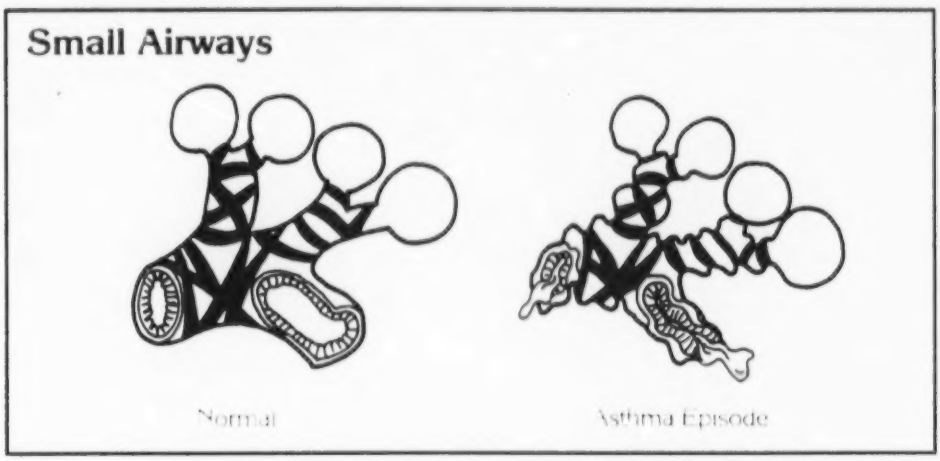
Recognizing early warning signs can give the person time to avoid an asthma episode he or she thinks is about to happen. The person can avoid the **trigger**, move away from the irritant, rest, or take medications. Early warning signs are different for each person, just as triggers are. These are some common early warning signs:

- Coughing, sneezing, runny nose, and dry, itchy, or scratchy throat
- Eyes that water, look glassy, or have dark circles under them
- Feeling weak, tired, spacey, sad, restless, or nervous
- Feeling a tightness in the chest
- Having skin that is pale, clammy, feverish, or that has broken out in a rash
- Parents may notice that small children want to be alone, or that they get quiet or are easily upset

There are other early warning signs. Children may identify their own by drawing a picture of how they feel before having an asthma episode and describing it to their parents. Older children may want to make a list to help them recognize these early signs. This is a big step toward self-care of asthma. By knowing their triggers and early warning signs, children can learn to prevent and control asthma episodes.

How is my child affected by asthma?

Children with asthma have difficulty breathing when they have an **asthma episode**. The muscles around the **bronchial tubes** tighten. This causes air to be trapped in the lungs. The lining of the **airways** swells and produces more mucus than usual, which further narrows air passages. The more severe an asthma episode, the longer it takes for the child to exhale. The child often coughs up mucus as the shortness of breath comes to an end. These changes are temporary and end when the asthma episode is over. However, **inflammation** of the airways may continue for weeks.



Do some children have more severe asthma than others?

Some people have more severe asthma than others. The disease varies from causing occasional mild wheezing to causing **steroid-dependent chronic illness**. Children with mild asthma often have different medications and treatments than children with severe asthma.

An individual child's asthma can get better and worse over time. Many children have fewer asthma episodes as they reach adolescence. Though they may always have a tendency to have "twitchy" lungs, they may not have asthma episodes after they begin puberty.

Some teenagers will continue to have asthma episodes throughout adolescence. These episodes are often less severe than when the teen was younger. Other teens may develop their first symptoms of asthma during adolescence. No one knows why people develop asthma at different ages.

What medications do children with asthma need?

Over-the-Counter (OTC) Medications

Over-the-counter medications are nonprescription drugs. Some may be harmful to children and adults who have asthma. For this reason, it is important to check with your doctor before using *any* OTC medication. Aspirin may cause asthma symptoms in some people. Aspirin is found in *many* over-the-counter medications. The scientific name for aspirin is **acetylsalicylic acid**. It may be listed this way on ingredient labels. OTC medications for asthma may have ingredients that affect the whole body. These nonprescription remedies can cause side effects such as increased heart rate. Prescription medications are available that affect only the airways and have little or no effect on the heart. In addition, some medications react with **theophylline** (a common oral medication for asthma) and can alter **blood levels**. It is safest to check with your doctor, nurse, or pharmacist before giving your child any nonprescription medications.

Inhaled Prescription Medications

Inhaled medication is often the first choice for the person with asthma. It is usually preferred because it works faster and requires lower dosages than **oral medications**. Oral medication must be taken in much higher dosages to be strong enough when it reaches the lungs. It also takes longer for oral medication to take effect. In addition, oral medication affects the whole body, while inhaled medication acts directly on only the areas that need it. Many types of asthma medication are available for inhalation.

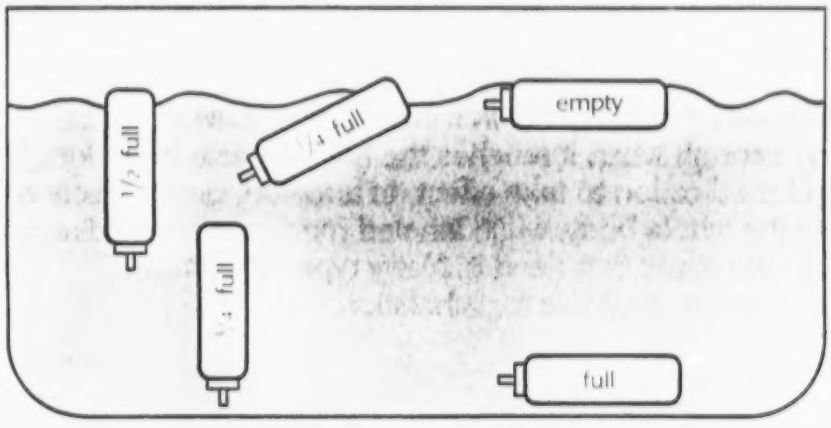
Types of Medication for Asthma

1. Beta Agonists - Inhaled Bronchodilators

Generic Name	Trade Names
albuterol	Proventil, Ventolin
isoproterenol	Aerolone, Isuprel
metaproterenol	Alupent, Metaprel
pirbuterol	Maxair
terbutaline	Brethaire

Many children with asthma will use some type of inhaled **beta agonist**. This type of medication quickly opens the airways. $Beta_2$ agonists work specifically on the airways and have little or no effect on the heart. Examples of $beta_2$ agonists are albuterol and terbutaline. Young children use this medication with a nebulizer or a reservoir device. The nebulizer produces a fine mist of medication that the infant or child breathes for several minutes. The reservoir device allows the child to breathe the medication when ready. Older children and teenagers usually use this medication with a **metered-dose inhaler**.

Estimating amount of medication left in your metered dose inhaler



2. Cromolyn Sodium

Generic Name	Trade Name
cromolyn sodium	Intal

Cromolyn sodium is a preventive inhaled medication that prevents asthma episodes by making the airways less likely to react to triggers. It needs to be used regularly to prevent asthma symptoms. Cromolyn does not stop an asthma episode

after it has started. Sometimes it can cause further constriction of airways if it is given during an **acute asthma episode**. Cromolyn is useful in preventing asthma episodes from allergies and exercise when it is used several times a day on a long-term basis.

3. Theophylline - Oral Bronchodilator

Generic Name	**Trade Names**
theophylline	Elixo-phyllin, Slo-bid, Slo-phylline, Somophyllin-CRT, Theobid, Theo-Dur

The most common oral medication to prevent asthma symptoms is **theophylline**. Theophylline is a **bronchodilator**, which means it opens the airways. It is chemically similar to caffeine. One advantage of this type of medication is that it lasts longer than inhaled medication. However, it has side effects such as nausea, loss of appetite, wakefulness, and restlessness. In some children, it may cause increased activity. Children who take theophylline and have behavior problems should discuss this with their physician. Lower **blood levels** of this medication may decrease the side effects. People who take theophylline need to have blood drawn periodically to check that the amount in their blood is normal. The level should be enough to control symptoms, but not too much. The usual effective, or **therapeutic range** is 10 to 20 **micrograms** per **milliliter** of blood. The blood level that will control symptoms is different for each child. Together, parents and physicians decide if the benefits of the medications outweigh the side effects.

4. Corticosteroids

Generic Name	**Trade Names**
Inhaled:	
beclomethasone	Beclovent, Beconase, Vanceril
flunisolide	AeroBid
triamcinolone acetonide	Azmacort
Oral:	
methyl prednisolone	Medrol
prednisone	Deltasone, Meticorten, Orasone

Corticosteroids or **cortisone** is a hormone produced by the human body in the **adrenal glands**. It is effective in controlling allergies, asthma, and other diseases. In severe asthma, when other medications do not control symptoms, extra cortisone often must be given. Cortisone can cause severe side effects,

so it is given in low dosages and for short time periods. When inhaled, cortisone affects the body much less than oral cortisone. This is because the inhaled dosage is less than the oral dosage. Inhaled cortisone affects target tissues in the lungs only. Very little reaches other tissues of the body. This is the preferred way to give cortisone for asthma. Oral cortisone can be used for a short time without severe side effects. It may be used for treatment of a severe asthma episode. Some doctors call this "short bursts of cortisone for acute **asthma flares**".

HEALTH CARE

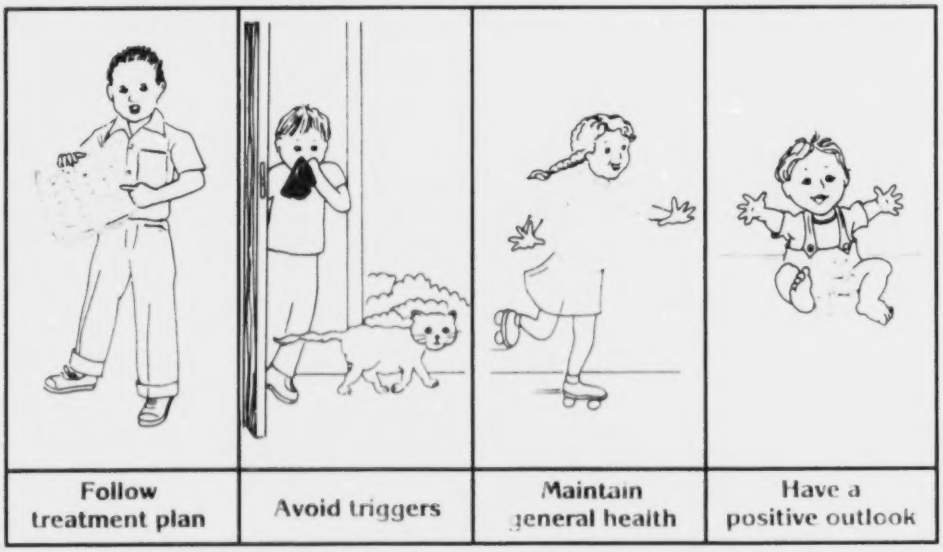
Many health care providers use the **Family-Centered Health Care Team** approach to treating a child or teenager with asthma. Using this approach, health professionals and the family decide together which treatments are best for the child. By coordinating and arranging for their child's health care, the family takes an active part in making the health care plan work.

Goals of Health Care

These are the goals of treatment for the child with asthma:

- Normal growth and development of the child
- Prevention of asthma symptoms
- Control of symptoms with the least amount of medication
- Normal **pulmonary** function
- Normal lifestyle with participation in the usual sports and activities of childhood and adolescence
- Knowledge of asthma and ability to manage the condition

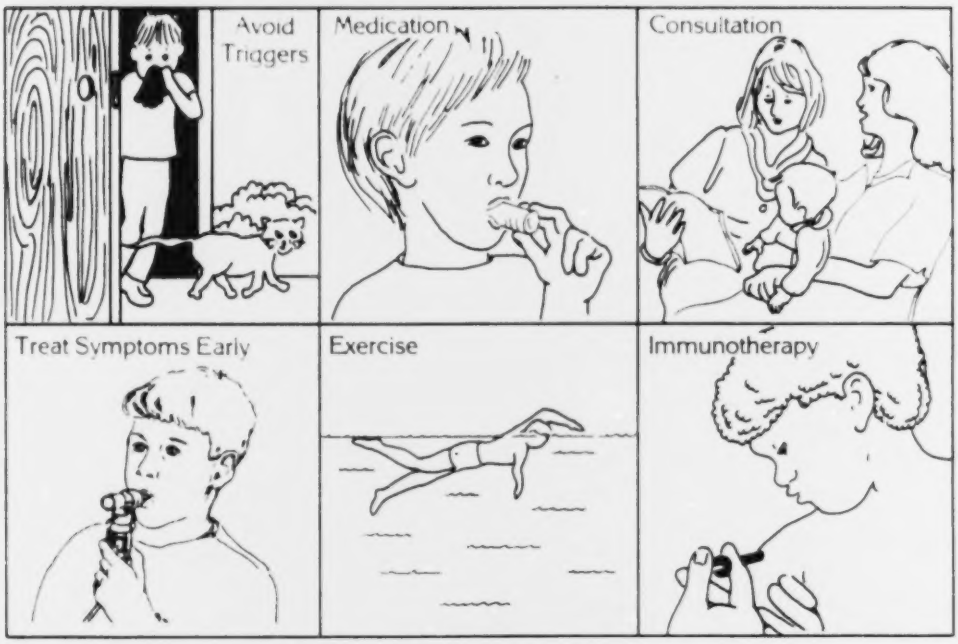
Avoid Asthma Episodes



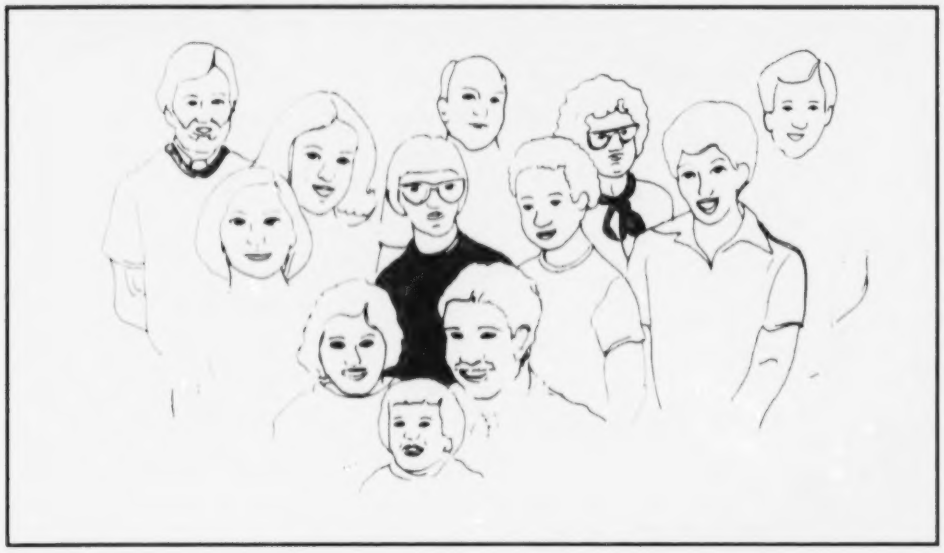
The goals of treatment can be accomplished through the effort of the family and the professional health team:

- Environmental change or modification
  - — Avoid **triggers** such as smoke, cold air, fumes, and others
  - — Make sure children with allergies have homes and schools that are free of pets, dust, plants and mold; they should have low-pile carpeting or no carpeting
- Asthma medications
  - — To prevent symptoms
  - — To treat asthma episodes
- Early treatment of asthma symptoms
- Exercise, with medication prior to activity if needed
- **Immunotherapy** to decrease sensitivity to **allergens** may be appropriate for some children with allergies.
- Health care team management.

Asthma Treatment



The Health Care Team



Members of the Health Care Team for the child or teenager with asthma include the following:

The Child or Teen and the Family — The most important members of the team!

- Provide personal and family health history
- Observe and describe signs and symptoms of asthma
- Record objective measurements such as **peak flow rate**
- Work with the rest of the team to plan and use treatments
- Communicate with the rest of the health care team about changes in the child's condition and the effectiveness of treatment and medications

Family Physician or Pediatrician — The primary doctor

- Performs well-child examinations, including hearing and vision tests
- Gives immunizations
- Monitors the child's growth and development
- Assesses child's **respiratory status**, sometimes using the **spirometry** test, and gives history and physical examinations
- Measures **blood levels** of theophylline
- Communicates with parents, teachers, and other professionals who are involved in the child's care
- Treats illnesses
- Prescribes medications
- Monitors the family's strengths, emotional well-being, and stress level

Pediatric Allergist — Doctor for children with allergies

- Tests for allergies, using **intradermal** or **scratch tests**
- Tests lung function with **spirometry** and other **pulmonary function tests**
- Takes a history of symptoms and monitors objective measurements such as **peak flow** measurements
- Examines ears, nose, throat, skin, and chest
- Gives allergy injections to some children with allergies
- Prescribes medications to prevent asthma symptoms and treat **asthma episodes**
- Consults with the family and the primary physician
- Recommends treatment for children with severe asthma

Pediatric Pulmonologist* — Doctor for children with lung conditions

- Monitors lung function with various **pulmonary function tests**
- Evaluates the treatment plan
- Prescribes medications to prevent asthma symptoms and treats **asthma episodes**
- Consults with the family and the primary physician
- Recommends treatment for children with severe asthma

Physical Education Teacher*

- Helps the family plan appropriate exercise
- Communicates with the school nurse, teachers, and family about asthma symptoms during physical education

Registered Nurse, Public Health Nurse, or Nurse Specialist *

- Gives preventive and educational counseling about asthma, procedures, and medications
- Develops a plan to control triggers in the **environment**
- Monitors the child's growth and development
- Monitors the child's **respiratory status**
- Helps the family coordinate health care
- Makes referrals to organizations and health professionals

Respiratory Therapist * — Lung treatment provider

- Teaches the family about nebulizer treatments and equipment
- Provides respiratory treatments

*These members of the health care team are optional, depending on how severe the child's asthma is.

School Nurse

- Helps the child and family coordinate the child's health care needs in school and school-related activities
- Develops a plan to control triggers in school
- Helps the child and family communicate health information to teachers and other appropriate school personnel
- Helps teachers provide an appropriate learning environment for the child
- Performs special health care procedures and gives medications in school

Periodic Health Care

Regular health care visits are important to your child's well-being. These visits are necessary to check your child's growth and development as well as his or her asthma. The schedule of regular visits will vary with the child or adolescent's age. However, as are all children, children with asthma are individuals and their needs will vary. ***Ask your doctor if your child's health care needs are different from those listed here.***

- Meet with your primary doctor for well-child examinations. The frequency of these visits will vary with your child's age.
- If your child's asthma is difficult to manage, meet with a pediatric allergist or pediatric pulmonologist every 3 to 6 months as recommended. The doctor will review your child's asthma treatment plan and make changes at this time. If your child's asthma seems out of control, meet with your doctor between visits to change the treatment plan.
- Children with asthma may need these tests from either their primary doctor or a specialist:
  - Measurement of respiratory function— **spirometry** every visit
  - Blood test for children who take oral **theophylline** to measure the level of theophylline in the blood. This is to make sure there is enough to control asthma, but not too much. The usual therapeutic or effective blood level for theophylline is from 10 to 20 **micrograms** per **milliliter** of blood. This test should be done about every 3 months.
  - Allergy testing if an allergic cause for asthma is suspected, if there is a strong family history of allergies, or if the child's asthma is severe. A small amount of many types of **allergens** are applied in these tests:

Scratch test - the skin is scratched with an **allergen**
Intradermal test - allergen injected under the skin
RAST-(radioallergoabsorbent test) — measures **IgE** in response to an **antigen** in a blood sample
FAST - similar test to RAST, done with fluorescence
Bronchial challenge test - uses **histamine** or **methacholine** to test airway reactivity; it is not used often with children

- Some children and teenagers receive treatments with a **nebulizer**. The physician who prescribes the treatment can instruct the family about treatments.
- Meet with the school nurse at the beginning of each year. Bring a list of topics to discuss with the nurse. A list is included in the information about schools in the Family Support and Services section of this booklet.
- If your child has **exercise-induced asthma**, you may want to meet with the school physical education teacher. Plan to control symptoms without limiting activity. Some doctors prescribe medication to be taken before exercise to prevent asthma symptoms.

These symptoms need medical attention between regular visits:

Many **asthma episodes** can be managed at home without having the child see a physician. Asthma treatment should focus on preventing asthma episodes. When asthma is kept in control, episodes will be less frequent and less severe. Develop a plan for treating asthma episodes with your doctor. Ask at what point you should bring the child in for medical care.

When the usual treatment for your child's asthma does not seem to be working, you and your doctor may need to change the treatment plan. Contact your doctor if your child experiences these events:

- Has more frequent **asthma episodes**
- Is not helped by medications within the usual amount of time
- Wheezes more frequently
- Coughs at night or with exertion
- Has a cold or respiratory infection that makes symptoms worse
- Becomes less active to control symptoms

These symptoms need *immediate* medical attention:

If the usual treatment for an **asthma episode** is not working, you may need to seek emergency medical care. Asthma episodes in some people *can* be life threatening. Some symptoms require immediate medical attention when home treatment doesn't work. If your child has *any* of these symptoms, seek emergency medical care:

- Medications do not help relieve the child's shortness of breath within the usual amount of time
- The child's color looks abnormal - pale or blue
- The child takes twice as long to breath out as in
- Muscles of the chest pull in with each breath
- Wheezing stops, but the child seems to be having more shortness of breath
- The child becomes very anxious during an asthma episode
- The child has difficulty breathing, itchy skin, or other symptoms after an insect sting or after taking a medication

Anytime you are concerned about a health problem, call a health professional for advice.

Record Keeping

Record keeping is an important part of coordinating your child's health care. Many parents find it helpful to keep records of their child's health care. Other parents prefer to rely on the records kept by their health care provider. If you keep records, you may want to use a loose-leaf notebook which can be divided into sections that fit your needs. A calendar can also be used to record this information. Section topics may include the following:

- Names, addresses and phone numbers of health team members
- Immunizations
- Appointment dates
- Daily care plans - treatments and medications
- Information about medications
- Changes in symptoms and **peak flow** measurements

A parent may find it useful to audiotape the doctor's instructions so that the spouse can hear the doctor's comments too. The family can also replay the tape later to review the instructions.

Some people also find it useful to make a list of questions before their appointment. It is easy to forget to ask questions during a short visit with a doctor.

THE CHILD'S NEEDS

Infants and Toddlers with Asthma — Ages 0 to 2

Health Care

- Infants and toddlers grow very fast. Medication dosages may need to be changed frequently during this period of fast growth.
- Sometimes children with asthma need to be hospitalized when they have a severe asthma episode. If the child is hospitalized, it is important to the child that parents be present as much as possible for comfort and support. Infants over 6 months old and toddlers often are fearful when separated from their parents.
- Remember that your child needs the same well-baby checkups and immunizations that all children need.
- These feeding practices seem to reduce the development of allergies (but not asthma): breastfeeding, waiting until the infant is 6 months old to slowly introduce solid foods, and avoiding feeding the infant cows' milk during the first year.
- It is important to control the child's **environment**. At home, avoid having pets, plants, and clutter that will collect dust. Throw rugs are better than carpeting because they can be washed. Keep the house free of smoke from wood stoves, cigarettes, and other sources. When away from home, try to avoid these triggers too.
- Infants and toddlers often use **nebulizer** treatments for asthma medications. These treatments can be used to treat or prevent asthma episodes. Some children use a preventive medication such as **cromolyn**. This medication must be used regularly to prevent asthma episodes. Cromolyn is *preventive*; it does not stop an asthma episode *after* it has started.

Development

- Provide a safe **environment** that allows the child to play with the least restriction. Provide toys and activities that are right for your child's age.
- All children are better able to manage life if they feel good about themselves. It is important to begin building your

child's self-esteem early by praising your infant or toddler often.

- When the child is feeling well, expect the same behavior from the child with asthma as from other children. Set limits on your toddler's behavior that are right for his or her age. Children who are not feeling well may regress in their behavior at times. They may want parents to do things for them that they previously did themselves. However, all children have the same needs for love and discipline.

Nebulizer

School

- Public Law 99-457 now requires schools to provide Early Intervention services to children with a **chronic condition** and a **developmental delay**. Most children with asthma do not qualify for this program. However, a child with asthma and delayed development may be eligible. This program provides services to children ages 0 to 3 years. Parents and a **multidisciplinary team** plan an **Individual Family Service Plan (IFSP)** for the child. Contact your local school district to find out how this program works in your area. Ask to speak to the Early Intervention Coordinator.

Day Care

- Avoid day care situations that have large groups of children, such as large day care centers. This will reduce the chance of the child developing **respiratory** infections.

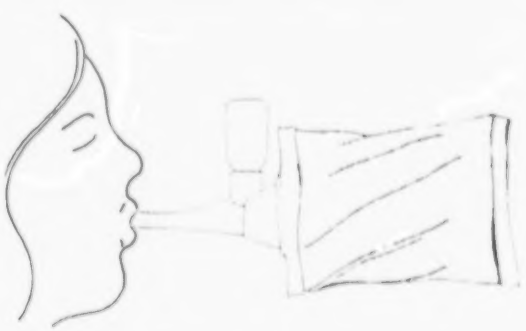
- If you decide that your child will attend day care, choose a provider who is willing to learn about caring for a child with asthma. Be sure you feel confident in the provider's ability to understand and carry out your instructions. Teach the provider any treatments they may need to do, such as giving medications, and using a **nebulizer**.
- Develop an emergency plan with the day care provider. Write a list of reasons to contact you. Include phone numbers for your doctor, several family members, and your number at work.

Preschool Children with Asthma — Ages 3 to 5

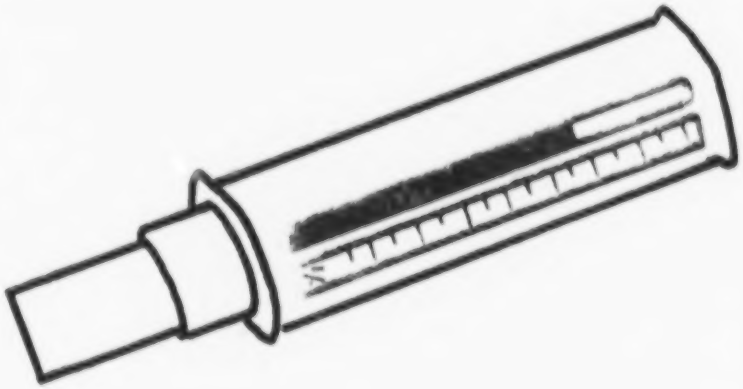
Health Care

- Continue regular health care as described in the Periodic Health Care section.
- Preschool children often use a combination of devices to receive asthma medications. Commonly, children use **nebulizer** treatments to treat or to prevent asthma episodes. Nebulizers produce a fine mist that is inhaled over several minutes. The mist is produced either by an air compressor or by **ultrasound**. Another method of giving medication is a **reservoir device** such as Inspir-Ease, which allows the child to inhale when ready. Most medications are available for use with a nebulizer or a reservoir device. You may want to discuss the advantages of each with your doctor, nurse, or respiratory therapist.

InspirEase®



- Some children use a preventive medication such as **cromolyn**. Cromolyn must be used regularly to prevent asthma episodes. This medication is *preventive*; it does not stop an asthma episode *after* it has started.
- **Theophylline** may make some children more active. Sometimes lower **blood levels** of this medication can reduce the tendency to overactivity. If your child has behavior or learning problems and takes theophylline, discuss this with your doctor. There may be alternative medications available.
- Asthma episodes can be anticipated and measured objectively with a **peak flow meter**. Children age 4 and older can usually use a peak flow meter. The child blows forcefully into the meter, and peak expiratory flow rate (the rate at which air leaves the lungs) is measured by the meter. The child self-tests daily to determine his or her normal value. Family members need to record the highest reading of three tries. If the reading drops to a number determined by the doctor, the child can take medication to prevent an asthma episode, or can contact the doctor. Early treatment of asthma episodes can prevent more severe episodes.



Peak Flow Meter

- It is important to control the child's **environment.** At home, avoid having pets, plants, and clutter that will collect dust. Throw rugs are better than carpeting because they can be washed. Keep the house free of smoke from wood stoves, cigarettes, and other sources. When away from home, try to avoid these triggers too.

Development

- Provide your child with simple information about asthma. A Preschool Family Asthma program is available through the American Lung Association of Minnesota. This program offers education and support to families. See the information on organizations in the Resources for Children with Asthma section of this booklet.
- Provide your child with opportunities to do the following:
  - — Play with other children of the same age
  - — Learn to start and complete activities when playing
  - — Have a balance between structured activities and free time to play
  - — Succeed, so he or she can gain self-confidence
- When the child is feeling well, expect the same behavior from the child with asthma as from other children. Children who are not feeling well may regress in their behavior at times. They may want parents to do things for them that they previously did themselves. However, all children have the same needs for love and discipline.

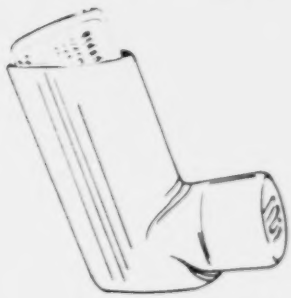
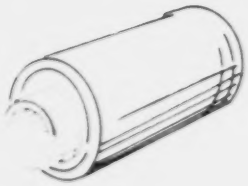
School

- At the beginning of each school year, meet with your child's teachers and the school nurse. Keep them informed of changes in your child's treatments and medications. See the information on schools in the Family Support and Services section of this booklet for a list of specific topics to discuss with school staff.
- Ask about pets and plants in the classroom before your child is assigned to a room.
- Explore opportunities for preschool for your child. A regular preschool is appropriate for most children with asthma. However, some children who have delayed development and other medical problems may be eligible for Early Childhood Special Education. For more information, contact your local school district to find out how this program works in your area. Ask to speak to the Early Childhood Special Education Coordinator.

School-Age Children with Asthma — Ages 6 to 12

Health Care

- Continue regular health care as described in the Periodic Health Care section.
- Most school-age children can learn to use a **metered-dose inhaler**. It is important that the inhaler is used correctly or the medication will not reach the lungs. A **spacer device** attached to the inhaler sometimes helps the child get more benefit from the medication. The spacer allows the medication to form fine particles. It also prevents medication from being deposited in the child's mouth and throat.

Metered-dose Inhaler	Spacer
	

- Some children use both a **nebulizer** and a metered-dose inhaler. Most medications are available in both forms. You may want to discuss the advantages of each with your doctor.
- Asthma episodes can be anticipated and measured objectively with a **peak flow meter**. Children age 4 and older can usually use a peak flow meter. The child blows forcefully into the meter, and peak expiratory flow rate (the rate at which air leaves the lungs) is measured by the meter. The child self-tests daily to determine his or her normal value. Family members need to record the highest reading of three tries. If the reading drops to a number determined by the doctor, the child can take medication to prevent an asthma episode, or can contact the doctor. Early treatment of asthma episodes can prevent more severe episodes.
- **Theophylline** may make some children more active. Sometimes lower **blood levels** of this medication can

reduce the tendency to overactivity. If your child has behavior or learning problems and takes theophylline, discuss this with your doctor. There may be alternative medications available.

- Most school age children are active. Some children with asthma may restrict their activity to prevent asthma episodes. If your child seems less active than other children of the same age, discuss this with your doctor. Medications taken before exercise will prevent most asthma episodes. Exercise is important for all children. In the child with asthma, exercise helps improve muscle development and builds stamina. Find sports that allow the child to self-pace activity and rest as necessary.
- It is important to control the child's **environment**. At home, avoid having pets, plants, and clutter that will collect dust. Throw rugs are better than carpeting because they can be washed. Keep the house free of smoke from wood stoves, cigarettes, and other sources. When away from home, try to avoid these triggers too.

Development

- School-age children understand factual information about asthma. Give them specific information about their condition. Camp Superkids, a program offered by the American Lung Association of Minnesota, teaches children about asthma while they attend an outdoor camp. The lung association also offers the Family Asthma Program, which teaches children and families about asthma.
- Allow your child increasing control over when to take medications for asthma episodes. Encourage the child to notice early warning signs of an asthma episode.
- Encourage your child to be responsible for remembering when to take preventive medications. At this age, children should also begin to decide whether they will expose themselves to an asthma trigger or not. Mastering self-care skills will give them self-confidence and a feeling of accomplishment.
- When the child is feeling well, expect the same behavior from the child with asthma as from other children. Children who are not feeling well may regress in their behavior at times. They may want parents to do things for them that they previously did themselves. However, all children have the same needs for love and discipline.

School

- Ask about pets and plants in the classroom before your child is assigned to a room.
- Meet with your child's teachers and the school nurse at the beginning of each year. Keep them informed of changes in your child's condition and treatment. See the information on schools in the Family Support and Services section of this booklet for a list of specific topics to discuss with school staff.
- Encourage your child to get involved in group activities for children his or her age.
- Check your school's policy on asthma medication. Children who can responsibly use their **metered-dose inhaler(s)** may have choices about carrying it with them at school. This allows the child to use the inhaler(s) at the first sign of breathing problems. Parents and the school nurse need to make a plan to check that the child is using the inhaler(s) as prescribed. The plan should include specific instructions for the child to seek help when breathing problems occur.
- If problems managing asthma occur at school, parents can arrange a conference with involved school staff. The conference may include teachers, the school nurse, the physical education teacher, and the physician.
- If your child is absent from school more than one day per month, check with your doctor about the need to re-assess your child's treatment plan. Also arrange for your child to receive homework from each class. If your child is absent for more than 15 days, request homebound services. A child is also eligible for homebound services sooner if he or she is absent frequently or the doctor expects an absence to last more than 15 days.

Adolescents with Asthma — Ages 13 to 17

Health Care

- Continue regular health care as described in the Periodic Health Care section.
- Adolescents primarily use a **metered-dose inhaler** for medication. It is important that the inhaler is used correctly or the medication will not reach the lungs. A **spacer device** attached to the inhaler sometimes helps the teenager get

Rotohaler® Inhaler
for Albuterol Powder from Capsules

more benefit from the medication. The spacer allows the medication to form fine particles. It also prevents medication from being deposited in the person's mouth and throat.

- If the teenager has exercise-induced asthma, ask your doctor whether the teen should take medication before exercise. School physical education teachers may help plan or adjust an exercise program. Swimming is one exercise that usually does not cause asthma symptoms. Encourage the teenager to find sports that allow self-pacing of activity and rest.
- Young women who take cortisone to control asthma must carefully plan pregnancies. Cortisone cannot be stopped suddenly. A young woman planning a pregnancy needs to ask her doctor about how medications for asthma may affect pregnancies.
- Encourage teenagers to control their **environment**. At home, avoid having pets, plants, and clutter that will collect dust. Throw rugs are better than carpeting, because they can be washed. Avoid smoke from wood stoves, cigarettes, and other sources. Encourage the teen to avoid these triggers when he or she is away from home too.
- Teenagers with asthma should not smoke, even if symptoms have decreased during adolescence. Smoking irritates the airways and can increase asthma symptoms. Smoking also can cause permanent damage to the lungs.

Development

- Some teenagers find it useful to belong to a support group for youths with asthma. These groups offer recreation and a chance for a young person to make friends with other teens who have similar concerns.
- Independence is necessary for teenagers to develop responsible behavior. Encourage the teen to decide about adjusting medication and treatments. Responsible behavior will usually follow independence, if the teen understands the benefits and consequences of his or her actions.
- Peers become increasingly important to teenagers. Teens with high self-esteem can resist peer pressure and are also less concerned about being different from their friends.

School

- Encourage the teen to be an advocate for him- or herself in school. The teen can keep school staff informed of changes in his or her condition and needs. Parents may need to be advocates for the teen at certain times during adolescence when the teen resists informing others of his or her condition and needs.
- Check your school's policy on asthma medications. Teenagers who can responsibly use their **metered-dose inhaler** may have choices about carrying it with them at school. This allows the teen to use the inhaler(s) at the first sign of breathing problems. Parents and the school nurse need to make a plan to check that the teen is using the inhaler(s) as prescribed. The plan should include specific instructions for the teen to seek help when breathing problems occur.
- If the teenager has problems managing asthma at school, parents can arrange a conference with involved school staff. The conference may include teachers, the school nurse, the physical education teacher, and the physician.
- If the teenager is absent more than one day per month, check with your doctor about the need to re-assess the teen's treatment plan. Also arrange for the youth to receive homework from each class. If the teen is absent for more than 15 days, request homebound services. A teen is also eligible for homebound services sooner if he or she is absent frequently or the doctor expects an absence to last more than 15 days.

Young Adults with Asthma — Ages 18 to 21

Health Care

- Continue regular health care as described in the Periodic Health Care section.
- Women who take cortisone medication for asthma need to carefully plan pregnancies. Cortisone cannot be stopped suddenly. When planning a pregnancy, a young woman needs to ask her doctor about medications for asthma that are safe during pregnancy.
- Determine if **triggers** have changed over time by noticing when symptoms appear. Also, when the young person moves, the new environment needs to be controlled for asthma triggers.
- When the young adult moves away from home or gets a job, find out if the current health insurance coverage continues. Some insurance policies will cover young adults only if they attend school as a full-time student. Discuss health insurance needs with your insurance company, social worker, public health nurse, or doctor.
- Young people who are planning to move away from home need to find a doctor in the new area before moving. The family doctor may be able to refer the young person to a doctor in the new area.

Development

- Young adults focus on life goals and careers. Asthma can influence career choices. People with asthma need to avoid triggers in the workplace. Some common triggers are chemical fumes in factories, and pollens and mold in farm work or plant nurseries. Other work that can trigger asthma symptoms includes working with Western Red Cedar wood, grain, animals and animal products. A young adult who is unsure of his or her career goals may want to seek assistance in career planning.

School

- When a young person goes away to college, he or she needs to plan for emergencies and illness. The young person also needs to plan regular follow-up care when home on vacation.

FAMILY SUPPORT AND SERVICES

Advocacy

Parents of children with **chronic conditions** need to learn to be advocates. A lot of advocacy is just teaching people about your child's condition. Parents understand their child's needs better than anyone else and have a lifelong relationship with their child. In contrast, health professionals come and go over time. Encourage your child to be an advocate for him- or herself as much as they can.

Another part of advocacy is being persistent in seeking a service or treatment that your child needs. If one person says you do not qualify for a service or that your child does not need a treatment, ask another person. Continue to tell health providers about your concerns until you are satisfied with their answers.

Finally, you may need to remind people who are treating your child about treating the whole child. Some health care providers will focus on one goal for your child's treatment, but may forget how that goal affects other areas of the child's life. An example of this is trying to fit treatments into a school schedule. You may need to discuss your child's treatment plan with school staff to best meet both school and treatment needs. If your treatment or medication plan is not effective in preventing asthma episodes, work with health care providers to plan an alternative that will work better.

Human Services

When a family member has a **chronic condition**, the family may feel financially strained. Several medical financial resources exist for families. Contact your local county human services office to find out if you are eligible for any of these. You may also call the agencies directly and ask them to send you eligibility information. See the information on health care financing in the section on Resources for Children with Special Health Care Needs for organizations that offer health care financial assistance.

Schools

Each year when your child starts school, meet with teachers and the school nurse to discuss the following:

- Your child's written Individual Health Plan (IHP)
- Your child's knowledge of asthma
- Your child's ability to self-manage asthma
- A list of all medications your child takes and their side effects
- The medications or treatments necessary at school
- The correct use of medications and a plan for their use
- Controlling asthma triggers in school; recognizing your child's triggers
- Planning for exercise
- Illness and asthma: when to keep your child home; when they can attend school with mild asthma symptoms
- Peak flow monitoring
- What to do in case of an asthma episode:
  - Telling the teacher or nurse about breathing problems
  - Use of medications, including inhalers
  - Notifying parents and/or the physician about problems
- Emergency phone numbers for family members and the doctor
- A plan for keeping school staff and family informed

Family Support Groups and Networks

Sometimes it is helpful for parents to talk to other parents of children with asthma. Other parents who have a child with the same condition can give encouragement and support with an understanding that comes from experience. You can find informal networks of parents through your doctor, pediatric nurse specialist, or social worker. The Association for the Care of Children's Health publishes a *Parent Resource Directory* that lists names and addresses of families of children with special health care needs across the United States. See the information on organizations in the section on Resources for Children with Special Health Care Needs at the end of this booklet for information on obtaining this guide.

Finding or starting a support group for teenagers with asthma may be helpful. A support group gives a teen a chance to talk to other teenagers with similar concerns. Support groups may also be available for families and siblings of teens with asthma. Family-to-family assistance can often give asthmatic teens and

their families insight into options in managing asthma care. Discussions may also help resolve the stress and emotional concerns that many families have. Check with your health provider or local hospital to find out if there is a group in your area. If not, you may be able to start one with the help of a social worker or nurse.

Recreation

With planning, most children with asthma can participate in all the usual childhood activities. Planning for activities may include using medication before participating in active sports. Treatment should focus on preventing symptoms that would limit activities for children with asthma. People with asthma have won Olympic medals for many sports including track. If your child has symptoms of asthma during exercise, review medications with your physician. Inform group leaders or coaches of your child's problems and needs.

Exercise is an extremely important part of asthma treatment. It develops muscles around the lungs and improves stamina. A child with asthma may tolerate some types of exercise better than others. Sports and activities that allow the child to pace him- or herself allow the child to rest when necessary. Swimming is an exercise that is well tolerated by children and youths with asthma. Some researchers think that the child or youth with asthma has fewer symptoms while swimming because the air the child breathes while swimming is humid. This may prevent the **airways** from drying and may prevent **exercise-induced asthma**. Gymnastics, yoga, and karate are also good because they encourage breath control and body awareness.

Travel

Families can prepare for travel by anticipating **triggers** in the new **environment** before leaving home. Try to avoid triggers, but be prepared with medication to prevent and treat symptoms. Bring enough medication for the entire trip and keep it near by. Don't check medications with baggage.

Check that equipment is complete. **Nebulizers** need to be in good working order and have all the attachments. If the nebulizer is battery powered, remember to bring the charger. If your child uses a **peak flow meter**, bring it along. Peak flow rates can alert parents to early signs of an asthma episode.

Be sure to bring health insurance information. When health care is not readily available, be especially well prepared. The International Association for Medical Assistance for Travellers (IAMAT) will help travelers locate an English-speaking doctor in foreign countries. See the organization information in the section on Resources for Children with Special Health Care Needs for more information.

Safety

Children with severe reactions to bee stings should carry an emergency kit with when they are involved in outdoor activities during warm weather. These kits contain a syringe with **epinephrine**, which counteracts the allergic reaction to bee stings.

Siblings

The brothers and sisters of a child with special health care needs have concerns other children don't have. They have many adjustments to make. They may have mixed feelings about their responsibility to the child with special health needs. They may feel guilty about being normal. They also may be angry that they do not receive as much "attention" as the child with special needs does.

Parents can help siblings adjust in several ways. Parents can give each of their children individual time without interruption. They can assure their children who don't have asthma that their feelings are okay. Relationships between siblings should stress friendship, rather than caregiving. The siblings of a child with asthma may benefit from the support of a person outside the immediate family. This may be a relative or a trusted friend. Other resource people may include school teachers, coaches, counselors and spiritual leaders. With support, children can grow through the experience of having a sibling with special health care needs.

GLOSSARY

acetylsalicylic acid (ASA) - The scientific or chemical name for aspirin, sometimes listed on labels his way.

acute asthma episode - Sudden, severe asthma symptoms which may not last long.

adrenal glands - Organs located on the kidney that produce corticosteroids.

airway - The passageway that air enters and leaves the lungs.

albuterol - A bronchodilator medication that is usually inhaled.

allergen or antigen - Any substance that causes an allergic reaction in the body.

alveoli - Small air sacs in the lungs.

anaphylaxis - An exaggerated reaction of the body to a foreign substance such as an insect sting or a medication. A type of shock.

asthma - A condition in which the airways tighten and produce thick mucus, making breathing difficult. Also called reactive airway disease.

asthma episode - Intermittent tightening of the airways, causing shortness of breath, wheezing, coughing, and increased mucus production. Also called an asthma attack.

asthma flare - Frequent asthma symptoms over days or weeks. Inflammation of the airways may cause these symptoms.

beta agonist - A bronchodilator medication that opens the airways.

blood levels - A blood test to determine the amount of a medication, such as theophylline, in the blood.

bronchi -Large airways in the lungs.

bronchial tubes - The large and small airways in the lungs.

bronchial challenge tests - A test to determine if a person's airways are reactive to histamine or methacholine. Pulmonary function tests are done, then the person inhales a nebulized mist, and repeats the pulmonary function test to see if the airways have reacted.

bronchioles - Small airways in the lungs.

bronchodilator - A medication that causes the airways to open.

chronic illness/condition - A disease or disability that affects a person for a long time.

community-based care - Services available as close to home as possible; within the community as defined by the family; includes the local doctor, clinic, outreach specialty clinics, the public health nurse, the school, public and private agencies.

corticosteroid - Hormones produced by the adrenal gland above the kidney. These hormones reduce inflammation in the body. Cortisone is one of these hormones.

cromolyn sodium - The generic name for Intal; a drug that seems to prevent asthma symptoms by stabilizing mast cells in the lungs. Cromolyn probably prevents mast cells from releasing histamine when an allergen is present.

culturally-appropriate - Care that is responsive to the values, beliefs, social norms, and behaviors of the individuals or populations being served; recognition of the values of different population groups. (From New England SERVE)

developmental delay - When children have not begun certain activities by the age that most children can perform the same activity. They may be slow to learn to talk, walk, feed and dress themselves, read, write, or other activities.

environment - In this context, the area that surrounds the child; where the child lives, plays, goes to school, and visits.

epinephrine - A hormone that helps the body respond to stress; also called adrenalin. The body produces it for the "fight or flight" response. In severe allergic reaction it is given by injection under the skin and quickly opens the airways.

exercise-induced asthma - Asthma symptoms that occur during exercise or physical activity.

exhale - To breathe out.

family-centered care - Health care that recognizes the family as the constant in the child's life, and that is flexible, accessible, and responsive to family needs.

family-centered health care team - A group of health professionals who work together with the family to provide the best care for each child with special health care needs.

FAST (fluoroallergoabsorbant tests) - A type of allergy testing done on a blood sample in the laboratory, using fluorescence.

generic name - A drug name not protected by trademark; usually descriptive of the drug's chemical structure.

histamine - A chemical that is released from body cells during an allergic reaction. It causes blood vessels to dilate (widen).

IgE - The allergic antibody that is intended to protect our bodies from foreign organisms and substances.

immunotherapy - Allergy shots to desensitize a person to specific allergens.

Individual Education Plan (IEP) - A plan for children receiving special education services; to meet a child's unique learning needs with a detailed plan.

Individual Family Service Plan (IFSP) - A plan to meet the unique needs of children with special needs ages 0 to 3 and their families; developed by a multidisciplinary team including the parents.

inflammation - Redness, swelling, and warmth of body tissue.

inhale - To breathe in.

Inspir-Ease® - A device for taking inhaled medication. It is a reservoir type device made by Key Pharmaceuticals.

intradermal allergy testing - Small amount of allergens are injected into the skin.

mast cells and basophils - These are white blood cells that contain histamine. Histamine from these cells is released in allergic reactions.

metered-dose inhaler or MDI - This is a small device that produces a fine mist of the medication to be inhaled.

methacholine - A drug sometimes used to test airway responsiveness in bronchial challenge testing.

microgram - A very small measurement of one-millionth of a gram in weight; it is abbreviated mcg. or µg.

milliliter - A measurement of one-thousandth of a liter in liquid volume; about 15 drops; it is abbreviated ml.

milligram - A measurement of one-thousandth of a gram in weight; it is abbreviated mg.

multidisciplinary team - A group of professionals from different fields who work together to give specialized services to the family.

mucus - Thick liquid made in the nose, throat, and lungs.

nebulizer - A small medication cup that produces a fine mist of the medication that is to be inhaled; the mist is produced with an air compressor or ultrasonic device.

oral medication - Medicine that is taken by mouth or swallowed.

peak flow meter - A simple tool to measure the air forced out of the lungs; an objective way to predict an asthma episode.

peak flow rate - The rate air is expelled from the lungs.

pulmonary - Pertaining to the lungs.

pulmonary function tests - Tests to check how well the lungs are working.

RAST (radioalleroabsorbant tests) - A type of allergy testing done on a blood sample in the laboratory.

reactive airway disease - Another name for asthma.

reservoir device - A container or sac that holds medication from a metered-dose inhaler until the child is ready to inhale.

respiratory tract - Pertaining to the nose, throat, airways and lungs.

respiratory status - The effectiveness of breathing and problems with breathing.

Rotohaler® - A small breath-activated device for inhaling albuterol powder from a capsule, made by Glaxo.

scratch allergy test - A method of testing for allergies by pricking the skin after a drop of allergen solution has been placed on the back.

spacer device - An extension tube that attaches to a MDI.

Spinhaler® - A device for inhaling cromolyn sodium powder from a capsule.

spirometry - A test that measures lung volume and the flow of air out of the lungs. The person blows into a tube connected to the spirometer.

steroid-dependent - A person who takes steroids, such as prednisone, over a long period of time. The dosage must be gradually decreased, so that the body will produce more of the hormone again.

theophylline - An oral medication for asthma that opens the airways; similar to caffeine.

therapeutic range - The blood levels of a medication that give the desired effect.

trade name - The name given to a drug by the company that manufactures it; protected by trademark.

trigger - A factor that causes asthma symptoms.

ultrasound - Very high frequency sound waves that are used to nebulize (make a fine mist of) medication; ultrasonic.

RESOURCES
for Children with Asthma

Organizations

American Academy of Allergy and Immunology
Learning Resource Center
611 East Wells Street
Milwaukee, WI 53202
(800) 822-2762

The Academy offers educational information to families. Pamphlets include *Exercise and Asthma, Allergy in Children, Tips for Teachers, Asthma and The School Child.* They are available on request. Videos include *Environment, Allergies and You, A Visit to the Allergy Doctor,* and *The Bee's Knees* on insect allergies. They are available for sale.

American College of Allergy and Immunology (ACAI)
800 East Northwest Highway
Palatine, IL 60067
(800) 842-7777

This organization offers patient education pamphlets for families. Subjects include information about theophylline, antihistamines, house dust, urticaria, allergic rhinitis, food allergies, asthma. It also offers ACAI Learning Center which provides information to physicians and other health professionals.

American Lung Association of Minnesota
490 Concordia Avenue
St. Paul, MN 55103
(612) 227-8014
(800) 642-LUNG (within Minnesota)

The association offers many services at the state level:

Camp Superkids on Lake Independence is for children 7 to 14 years old who take daily medication for asthma. It is a residential summer camp.

Camp We-No-Wheeze South (Rochester) and North (Duluth) are alternatives to Camp Superkids. They are weekend camps and are therefore less expensive.

Open Airways Family Asthma Program is an education program for families. Call the ALA of Minnesota for locations and times. For families of children 3 to 5 years old, ALA offers the Preschool Family Asthma Program.

Publications about asthma for children and teenagers include educational booklets and *Asthma Update* newsletter.

Support groups and networks for families. Call for more information.

Asthma and Allergy Foundation of America (AAFA)
1717 Massachusetts Avenue NW, Suite 305
Washington, D.C. 20036
(800) 7-ASTHMA

Call the toll-free phone number for information about asthma and allergies. The foundation has patient education programs for asthma. It also has videos and brochures about asthma and allergies. AAFA sponsors a support group for parents and adults with asthma in the Twin Cities metropolitan area.

Breathing Easy - Asthma Information and Support
Children's Hospital of St. Paul
345 North Smith
St. Paul, MN 55102
(612) 220-6120

This ongoing group offers free information and support. Parents of children any age and children 4 to 18 years old have concurrent meetings one evening each month. Guest speakers address topics such as basics about asthma, medications and side effects, school and psychosocial issues, teaching children responsibility, and how to manage asthma. The group holds a family picnic during the summer. Teens Controlling Asthma is a series of 6 classes for teens 13 to 18 years old. Teens meet with other youths and health professionals to learn about managing asthma and discuss their concerns. Snacks are provided.

LUNG LINE
National Jewish Center for Immunology and Respiratory Medicine
1400 Jackson Street
Denver, CO 80206
(800) 222-LUNG

The Lung Line is a free consumer information service. Registered nurses answer questions, send literature, and help callers find help for their medical concerns.

Mothers of Asthmatics (MA)
10875 Main Street, Suite 210
Fairfax, VA 22030
(703) 385-4403

MA is a nonprofit organization devoted to helping families overcome the hardships of asthma through education, awareness of medical advancements, and quality resources. It offers *The MA Report*, a monthly newsletter for parents of children with asthma. Write or phone for a sample copy. It also offers written materials about support, peak-flow monitoring, an asthma and allergy resource guide, and a book titled *So You Have Asthma Too* for children with asthma.

National Heart, Lung and Blood Institute
NIH Building 31, Room 4A21
9000 Rockville Pike
Bethesda, MD 20892
(301) 496-4236

The institute offers pediatric self-management programs for children with asthma: Air Power, Air Wise, Living with Asthma, and Open Airways. Order forms are available through this office. It offers an asthma Reading and Resource List also.

Books, Pamphlets, and Videos
for Children and Families

Many of the books listed here are available through the Minnesota public library system. Books that are not available in the local library can be borrowed from any other public library in Minnesota.

Air Currents. This newsletter about asthma is available free to families. For subscription, write to Allen & Hanbury's Respiratory Institute, Air Currents, 5 Moore Drive, Research Triangle Park, NC 27709.

Althea. 1983. *I Have Asthma.* Dinosaur Publications Ltd., Cambridge, England. (For preschool and school age children). A school-age boy tells what it's like to have asthma. Available from Woozles Books, 1533 Birmingham St, Halifax, Nova Scotia, Canada B3J-2J6. Phone (902) 423-7626.

American Lung Association (ALA) Publications:

The Asthma Handbook - 24-page booklet for youth and adults, *Asthma Update* - A newsletter for families published by the St. Paul ALA. To receive the newsletter, phone (800) 642-LUNG. *Catalog* - A list of materials published by the ALA *Superstuff* - Games and a booklet for children with asthma.

Asthma and Allergy Foundation of America (AAFA):

Advance. The bi-monthly newsletter of AAFA is available with membership in AAFA and at some doctors' offices.

Asthma Care Training Program. This VHS video shows an education program to help children with asthma learn to take charge of their health. It teaches decision-making skills. 15 minutes.

Auxiliary Inhalation Devices. This VHS video shows proper use of nebulizers, spacer devices, spinhalers, and metered-dose inhalers by adults and children. 21 minutes.

Asthma and Allergies in the School: The Importance of Cooperative Care. This VHS video shows a patient/parent-teacher education program that promotes communication and cooperation of everyone involved in the care of a child with asthma while at school. 12 minutes.

The Jeanette Bolden Story. This VHS video shows the inspiring, real-life story of a young woman with severe asthma who wins a 1984 Olympic Gold Medal for track. 12 minutes.

The Asthma Team Newsletter. Written for children with asthma. 3 issues per year. Write for subscription information: American Lung Association of Western Pennsylvania, 2851 Bedford Avenue, Pittsburgh, PA 15219.

Asthma Update. This newsletter, published four times per year, reports current research on asthma. It also includes methods for coping with childhood asthma. For subscription information write to Asthma Update, 123 Monticello Avenue, Annapolis, MD 21401.

Gershwin, M.E. 1986. *Asthma: Stop Suffering/Start Living.* Addison-Wesley Publishing, Reading, MA. 219 pages. This book describes strategies for controlling asthma including diet, medication, exercise, and self-care.

Loomis, C. 1987. Childhood Asthma: What You Should Know. *Parents Magazine.* 62(May): 227-8, 232-4.

The MA Report. This newsletter, published monthly is for parents of children with asthma. Write or phone for a sample copy to Mothers of Asthmatics, 10875 Main Street, Suite 210, Fairfax, VA 22030. (703) 385-4403.

Mendoza, G., et al. 1988. *Users Guide to Peakflow Monitoring.* Mothers of Asthmatics, Fairfax, VA. This handbook describes how to do peak-flow monitoring; it contains a question-and-answer section.

Plaut, T. 1988. *Children with Asthma: A Manual for Parents.* Pedipress, Amherst, Massachusetts. This book includes information about asthma, medications, coping with the condition, what to do for vacations and other subjects.

Sander, N. 1989. *A Parent's Guide to Asthma.* Doubleday, New York, NY. Sander is the founder of Mothers of Asthmatics. This book for families includes practical family-centered advice and an extensive resource list.

Weinstein, A. 1987. *Asthma.* McGraw Hill, New York, NY. An extremely comprehensive self-care book on managing asthma.

Articles and Books
for Health Professionals

American Lung Association Publications:
Asthma Alert Informational File Folders for teacher, school nurse, physical education teacher, and school administrator.
Catalog of publications.
Standards for the Diagnosis and Care of Patients with Chronic Obstructive Pulmonary Disease and Asthma. 1987.

Bailey, W.C., Keens, T.G., and Tinstman, T.C. 1987. Plotting a Course for Asthma Therapy. *Patient Care.* May 15, 1987: 62-82.

Bureau of Maternal and Child Health. 1989. Guidelines for the Care of Children with Chronic Lung Disease. *Pediatric Pulmonology.* Supplement 3.

Cherniack, R.M. 1987. Continuity of Care in Asthma Management. *Hospital Practice.* 22(9); 119-143. Sept. 15th.

Evans, D., Clark, N., and Feldman, C. 1987. School Health Education Programs for Asthma. *Clinical Review of Allergy.* 5: 207-212.

Fireman, P. (Editor). 1988. Pediatric Allergic Disease. *Pediatric Clinics of North America.* 35(5).

Mendoza, G. 1988. *Peak Performance: A Strategy for Asthma Self-Assessment.* Mothers of Asthmatics, Fairfax, VA. Peak-flow monitoring written for physicians and other health professionals.

Molitor, L. 1986. An Asthmatic Preschooler: Assessing Respiratory Distress. *Journal of Emergency Nursing.* 12(6): 405-6.

Nemec, M.A. 1987. Inhalational Medications for Chronic Asthma. *Journal of Pediatric Health Care.* 1(4): 223-7.

Reyes de la Rocha, S. and Brown, M. 1987. Asthma in Children: Emergency Management. *Annals of Emergency Medicine.* 16(1): 79-89.

Sheller, J.R. 1987. Review: Asthma, Emerging Concepts and Potential Therapies. *American Journal of the Medical Sciences.* 293(5):298-308.

Shohat, M. 1987. Diagnosis, Management and Prognosis of Asthma in Children. *Comprehensive Therapy.* 13(10): 7-13.

Tinkelman, D.G. 1988. Theophylline - Use and Misuse in Pediatric Asthma. *Hospital Practice*. Feb. 15, 1988: 179-184.

Traver, G. and Martinez, M. 1988. Asthma Update. Part 1, Mechanisms: Pathophysiology and Diagnosis. Part 2, Treatment. *Journal of Pediatric Health Care*. 2(5): 221-233.

Wabschall, J. 1986. Nursing Management of Children during a Mild to Moderate Asthma Attack. *Journal of Emergency Nursing*. 12(3): 134-141.

Specialty Medical Care
for Children with Asthma

Children with mild asthma can usually receive all their care from their primary doctor. If the child's asthma is difficult to control, the primary doctor may refer the child to a specialist. Specialists for children with asthma are usually pediatric pulmonologists (children's lung specialists) or pediatric allergists (children's allergy specialists).

Children's Hospital of St. Paul
345 North Smith Avenue
St. Paul, MN 55102
(612) 220-6000 or 220-6700

Duluth Clinic
400 East 3rd Street
Duluth, MN 55805
(218) 722-8364

Group Health
(Many locations)
Member Service Department
2829 University Avenue SE
Minneapolis, MN 55414
(612) 623-8550

Mayo Clinic
Pediatric Clinics
200 First Street SW
Rochester, MN 55905
(507) 284-2511

Minneapolis Children's Medical Center
2525 Chicago Avenue South
Minneapolis, MN 55404
(612) 863-6111

Park Nicollet Medical Center
5000 West 39th Street
Minneapolis, MN 55416
(612) 927-3123

University of Minnesota
Pediatric Clinics
516 Delaware Street SE
Minneapolis, MN 55455
(612) 626-6100

Please note:
This is a partial list of resources available in Minnesota. We do not endorse any specific organizations or publications. You will need to evaluate the quality of the services and determine if they fit your individual situation.

GENERAL RESOURCES

for Children with Special Health Care Needs

Organizations

Association for the Care of Children's Health (ACCH)
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
(301) 654-6549

ACCH publishes a variety of materials for families and professionals. It offers a newsletter, brochures and booklets, and videos to help families get the most out of the health care system. It also publishes the *Parent Resource Directory,* which contains the names and addresses of parents whose children have special health needs. Parents are listed by area and by their child's condition. The Minnesota chapter is coordinated by a parent. Call or write the national organization to for the current chapter address. Send for the ACCH publications catalog.

County Public Health Nursing Agencies
Minnesota Department of Health
Section of Public Health Nursing
717 Delaware Street SE, P.O. Box 9441
Minneapolis, MN 55440
(612) 623-5468

Each county in Minnesota offers public health nursing services to residents of the county. Some counties offer respite care services or can help families locate respite care. The local agency may also help teach family members and babysitters about the care of the child with special health care needs. Contact your local county, or call the Minnesota Department of Health to locate your local office.

County Social Services
Minnesota Department of Human Services
444 Lafayette Road
St. Paul, MN 55155
(612) 296-6117

County social services offer support and assistance in finding local resources for families such as equipment, respite care, financial aid and intervention services. It also offers care coordination to families. Call your local county for information.

Courage Center
3915 Golden Valley Road
Golden Valley, MN 55422
(612) 588-0811

Courage Center offers services to children and adults with physical disabilities and speech, hearing and vision impairments and services are also available to family members. It offers adaptive driver education, a Communication Resource Center, camping experiences, a transitional residence program, support programs, physical and occupational therapy, and recreational and athletic activities. *Meeting Ground* is a free bimonthly newsletter written by and for families and health professionals. Call or write for a subscription.

The Early Intervention Project
Minnesota Departments of Health, Education and Human Services
Call your local school district for information.

The Early Intervention Project is a federally mandated program that operates through local interagency committees. Its purpose is to provide services for children from birth to three years of age who have special health care needs or developmental delays. Services may include respite care, public health nursing services, physical therapy, occupational therapy, speech and language therapy, early childhood special education, special equipment, family support activities, and training for parents.

Federation for Children with Special Needs
95 Berkeley Street
Boston, MA 02116
(617) 482-2915

The Federation for Children with Special Needs provides information and resources that focus on improving communication between families and health professionals. It also offers support for parents of children with special needs.

International Association for Medical Assistance to Travellers
IAMAT - USA Membership Office
417 Center Street
Lewiston, NY 14092

IAMAT is an organization that publishes a directory of English-speaking physicians around the world. Fees for visits are set at

low rates. It also offers health information for travelers. The membership and directory are free. Voluntary contributions are encouraged.

MedicAlert Foundation International
Turlock, CA 95381-1009
(800) ID-ALERT

MedicAlert makes identification necklaces and bracelets. The tags list medical information such as diagnosis, medications, and allergies. When someone purchases an ID, MedicAlert keeps a brief medical record on computer, which is updated yearly. Emergency medical personnel can call for more specific information than can be listed on the ID.

Metro Center for Independent Living (MCIL)
1619 Dayton Avenue, Suite 303
St. Paul, MN 55104
(612) 646-8342 (voice or TDD)
(612) 642-2507 (FAX)

MCIL offers transitional programs to promote independent living. Its Used Equipment Referral Service is a network between sellers, buyers, and donators of used equipment. It matches people who need equipment with those who have equipment available. Equipment includes wheelchairs, bathroom equipment, ramps, lifts, vehicles, hospital beds, walkers, prone standers, and more.

Minnesota Department of Health
Genetics Unit
717 SE Delaware Street
Box 9441
Minneapolis, MN 55440
(612) 623-5269

Families can call the Genetics Unit to locate resources for genetic counseling for conditions that have a possible hereditary component.

Minnesota Department of Health
Services for Children with Handicaps (SCH)
717 Delaware Street SE, P.O. Box 9441
Minneapolis, MN 55440
(612) 623-5150 (voice or TDD)
(800) 728-5420 (toll-free voice or TDD)

SCH offers community-based clinics and services, health education and support programs, and health care financing to families of children with special health care needs. It also offers technical consultation to health professionals. SCH has district offices in Bemidji, Duluth, Fergus Falls, Mankato, Marshall, Minneapolis, Rochester, St. Cloud, and Virginia. Call for more information.

Minnesota State Council on Disability
145 Metro Square Building
7th Place and Jackson Street
St. Paul, MN 55101
(612) 296-6785 (voice or TTY)
(800) 652-9747 (Ask for Minnesota State Council on Disability)

This is an information and referral resource for people with disabilities who live in Minnesota.

National Center for Youth with Disabilities
Adolescent Health Program
University of Minnesota
Box 721 - UMHC
Harvard Street at East River Road
Minneapolis, MN 55455
(612) 626-2825
(800) 333-6293

The center offers services to families, youth, and professionals to assist them in developing alternative service systems, which will allow adolescents and young adults to develop to their fullest capacity. It offers a National Resource Library and technical assistance by a network of professionals from many disciplines. The center also fosters the development of community-based services through a national network of federal and state information.

National Information Center for Handicapped Children and Youth (NICHCY)
P.O. Box 1492
Washington, D.C. 20013
(703) 893-6061

NICHCY is a national clearinghouse that provides information about many handicapping conditions. It also offers a list of parent groups throughout the United States and information regarding available services to disabled people.

National Rehabilitation Information Center
8455 Colesville Road
Suite 935
Silver Spring, MD 20910
(800) 346-2742

This organization offers a computer information service called ABLE DATA. Call for information.

PACER Center (Parent Advocacy Coalition for Educational Rights)
4826 Chicago Avenue South
Minneapolis, MN 55417-1055
(612) 827-2966 (voice & TDD)
(800) 53-PACER (toll-free)

PACER Center offers statewide workshops for families of handicapped children. The workshops inform parents of schools' rights and responsibilities to provide free appropriate education programs for children. Specific information is provided about Public Laws 94-142 and 99-457. Written materials are available in English, Spanish, and Hmong languages.

Pathfinder Resources
2324 University Avenue West, Suite 105
St. Paul, MN 55114
(612) 647-6905

Pathfinder works to improve the health and well-being of children with chronic conditions. It offers consultation and technical assistance in networking, education, public policy and financing, and publications.

Pilot Parents of Minnesota
201 Ordean Building
Duluth, MN 55802
(218) 726-4745

Pilot Parents is a parent network that matches families who have children with similar health or developmental conditions. Parents are trained to give information about services and educational programs, and can offer emotional support. Parents are available in most areas of Minnesota including northeastern, northwestern, central, and southeastern Minnesota. Pilot parents hope to have families available in southwestern Minnesota in 1991.

Siblings for Significant Change
105 East 22nd Street
Room 710
New York, NY 10010
(212) 420-0776

This Organization for siblings of disabled people. It offers information and referral services, counseling programs, and community education.

Sibling Information Network
Connecticut's University Affiliated Program
991 Main Street
New Hartford, Connecticut 06108

This is a clearinghouse of information for the siblings and families of disabled people. It offers quarterly newsletters with reviews, resource information, and discussions of family issues.

Wilderness Inquiry
1313 Fifth Street SE
Suite 327A
Minneapolis, MN 55414
(612) 379-3858

Wilderness Inquiry provides challenging wilderness experiences for physically disabled and nondisabled people. The camping trips require interdependence and cooperation. Experiences are available for families with children. Young adults over 18 years old may attend without family members. Some trips are available to teens 13 to 18 years old.

Books, Pamphlets, Videos, and Catalogs of Information

Adams, B. 1979. *Like It Is: Facts and Feelings about Handicaps from Kids Who Know.* Walker & Co., New York, NY. 96 pages. This book is written for school-age children and adolescents.

Aspen Publications. *Infants and Young Children.* 1600 Research Boulevard, Rockville, MD 20850. This journal is for parents and professionals who work with children. For more information phone (800) 638-8437.

Association for the Care of Children's Health, 1987. *Family-Centered Care for Children with Special Health Care Needs.* ACCH, Bethesda, M.D. 74 pages. This book describes family-centered health care. Each chapter has a section that contains specific ideas to "make it happen." The final chapter includes checklists to help evaluate how well health providers are collaborating with families.

Association for the Care of Children's Health, 1988. *Seasons of Caring.* ACCH, Bethesda, M.D. 40-minute videotape. Reveals the strengths and needs of families caring for children with special health care needs. Addresses many issues encountered by parents, teachers, social workers, school administrators, nurses, physicians, and others who care for children with special needs and their families. Another 38-minute video, *Family-Centered Care,* shows the experiences of several families around the country.

Beckett, J. 1990. *Health Care Financing: A Guide for Families of Children with Special Health Care Needs.* National Maternal and Child Health Resource Center, University of Iowa, Iowa City, IA, 52242. 77 pages. This publication is an introduction to private and public funding. It also includes a private insurance checklist and a resource list.

The Exceptional Parent. 605 Commonwealth Ave., Boston, MA 02215. This is a consumer magazine for parents of children with chronic conditions. The magazine is published eight times per year. It contains articles that provide practical information and emotional support for families.

Exley, H. (editor). 1984. *What It's Like to be Me.* Friendship Press, New York, NY. 127 pages. This book is written and illustrated entirely by disabled children. It's intended for school-age children and those in early adolescence.

Haig, B. and Moynihan, P. 1988. *Whole Parent/Whole Child: A Parent's Guide to Raising the Child with a Chronic Health Condition.* Diabetes Center, Minneapolis. How to help the child with a chronic health problem lead the fullest life possible. This book is written for families and health professionals who care for children with many different conditions.

Harnish, Y. and Leeser, I. 1984. *Patient Care Guides: Practical Information for Public Health Nurses.* National League of Nursing, New York, NY. 211 pages. This book has a section that contains patient care guides for children with chronic conditions. Some of the conditions included are mental retardation, myelodysplasia, neurological handicaps, muscular dystrophy, and cleft lip and palate.

Healy, A. and Lewis-Beck, J. 1987. *Guidelines for Families, Guidelines for Nurses, Guidelines for Physicians, Guidelines for Social Workers, Guidelines for Therapists.* University of Iowa Bookstore, Iowa City, IA 52242. Each of these booklets describes specific actions that can improve health care of children with chronic conditions.

Imagine Me. 1987. Innercare, 322 First Avenue North, Suite 320, Minneapolis, MN 55401. (800) 727-7794. *Imagine Me* is a learning kit to help children with chronic disorders that cause discomfort learn to control their distress. It includes audiotapes for the child and parents, a practice book, a progress chart, tools, and a "Body Boss" Bear.

Larson, G. (Editor), 1986. *Managing the School Age Child with a Chronic Health Condition.* Pathfinder and the School Nurse Organization of Minnesota, DCI Publishing. 335 pages. This book is a practical guide for schools, families, and organizations. A family may find it useful to review and discuss chapters about its child's condition with school personnel.

Mitchell, J. 1980. *See Me More Clearly: Career & Life Planning for Teens with Physical Disabilities.* Harcourt Brace Jovanovich, New York, NY. 284 pages. A comprehensive guide for youth with disabilities. Includes a section titled "Charting Your Course: Life Career Skills."

National Center for Education in Maternal and Child Health (NCEMCH). 1989. *Reaching Out: A Directory of National Organizations Related to Maternal and Child Health.* 38th & R Streets, NW, Washington, DC. This resource guide lists organizations by specific disease or disability.

National Maternal and Child Health Clearinghouse (NMCHC) 1988. *Publications Catalog.* 38th & R Streets NW, Washington, DC 20057. 22 pages. Catalog of publications available through NMCHC. Most of these publications are free. One section lists publications about children with special health care needs.

Neibuhr, S., and Royse, J. 1989. *Take Care.* Wilder Foundation, 919 LaFond Avenue, St. Paul, MN 55104. (612) 642-4060. 31 pages. A guide for caregivers on how to improve their self-care.

Pediatrics for Parents. This newsletter is written to help parents understand pediatrics and health care issues so they can become informed, active participants in their child's health care. 10 issues per year. Write or phone for subscription information: Pediatrics for Parents, 348 Broadway, PO Box 1069, Bangor, MD 04401. Phone (207) 942-6212.

Randall-David, E. 1989. *Strategies for Working with Culturally Diverse Communities and Clients.* Association for the Care of Children's Health. Bethesda, M.D. 96 pages. This guide is written to help professionals learn to provide culturally appropriate care to families and communities. It includes sections on assessing your own cultural heritage, learning about the community, working with culturally diverse groups and using interpreters.

Routburg, M. 1986. *On Becoming a Special Parent: A Mini-Support Group in a Book.* Parent/Professional Publications, Box 59730, Chicago, IL 60645. Chapters on adjustment, equipment and toys, hospitals, respite, health care, medication, therapy, advocacy, individualized education program (IEP), and more.

Segal, M. 1988. *In Time and With Love: Caring for the Special Needs Baby.* Newmarket Press, New York, NY. 192 pages. For families and caregivers of preterm and handicapped children ages birth to 3 years. Information is included about coping; nursing, feeding, and dressing; social skills; games and activities; discipline; and decision making.

Health Care Financing

There are many types of health care financing available to families with children with special health care needs. Each plan covers different services. Eligibility requirements also differ. Listed are some of the most common payment systems. Contact your local county human services office or the providing agency to find out if you are eligible for any of these.

Children's Health Plan (CHP)
444 Lafayette Road
St. Paul, MN 55155-3829
(612) 297-3862
(800) 652-9747 (Ask for Children's Health Plan)

The Children's Health Plan offers health care insurance for under insured or uninsured children 1 through 17 years old. Coverage costs $25 per year, per child. Eligibility is based on income and family size.

Medical Assistance Program (MA)
Minnesota Department of Human Services
444 Lafayette Road
St. Paul, MN 55155
(612) 296-3386
(800) 652-9747 (Ask for Medical Assistance)

Medical Assistance offers health care financing for families. Eligibility is based on income and family size. Children with chronic health conditions may qualify for full Medical Assistance benefits based on their income and assets alone under a waiver. For information, call your county human services office or the state office listed here. Local county human service agencies may also have funds under Title XX Social Service Programming, Family Subsidy, or Permanency Planning Grant.

Waivers

Waivers provide medical assistance benefits to children counting only the child's income and assets to determine eligibility. Expenses covered vary with each type of waiver.

Children's Home Care Option (TEFRA 134)
Medical Assistance is offered under the Children's Home Care Option or TEFRA. Children must be certified as disabled by the Social Security Administration or the State Medical Review

Team. Children are cared for at home. Eligible children have all regular medical assistance expenses covered.

Community Alternative Care (CAC)
The program offers home and community care services for chronically-ill children. Children must be residents of a hospital or be likely to need inpatient hospital care. The program covers expenses for care that cost less than it would at an institution covered by Medical Assistance.

Community Alternatives for Disabled Individuals (CADI)
This program covers applicants to or residents of nursing care facilities. The person must be certified as disabled. Children are cared for at home. The program offers home and community care services for disabled individuals under age 65. It covers expenses for care that cost less than they would at an institution covered by Medical Assistance.

Home and Community Based Waiver for Persons with Mental Retardation or Related Conditions (MR/RC)
Individuals diagnosed with mental retardation or a related condition of any age are eligible. The person is cared for at home. This waiver covers expenses for care that cost less than it would at an institution covered by Medical Assistance.

Services for Children with Handicaps (SCH)

Minnesota Department of Health
717 Delaware Street SE, P.O. Box 9441
Minneapolis, MN 55440
(612) 623-5150 (voice or TDD)
(800) 728-5420 (toll-free, voice or TDD)

Services for Children with Handicaps offers financial help for health care to children with special health care needs. Eligibility is based on diagnosis income and number of family members. SCH serves children from birth to age 21 years. Services for Children with Handicaps has district offices in Bemidji, Fergus Falls, Virginia, Duluth, Marshall, St. Cloud, Minneapolis, Mankato, and Rochester.

Notes:

Minnesota Department of Health
717 Delaware St. S.E.
P.O. Box 9441
Minneapolis, MN 55440